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Patients' views on care and their association with outcomes in palliative care

When patients face advanced illness, their *experience* of care is especially important. In palliative care, we often rely on the accounts of bereaved relatives to report the quality of end-of-life care, and there are no validated patient-reported measures of the experience of care. We report therefore on a new questionnaire, Views on Care (VOC), to address this gap. It consists of four questions (see the following link for full questionnaire: www.pos-pal.org) selected/refined from St Christopher's Index of Patient Priorities (SKIPP)¹, which address patients' evaluation of (1) change in their main concerns, (2) benefit from palliative services, (3) previous and (4) current quality of life (3 and 4 adapted from EORTC QLQ-C15-PAL – well-validated in advanced illness²).

Methods

We conducted a survey to examine patients' views on care (using VOC) and the relationship between these views and changes in health status. Participants were adults receiving specialist palliative care in eight hospital, hospice inpatient and community settings across England, recruited in 2014–2015. We collected demographic details (age, gender, ethnicity, marital status, if living alone, presence of informal caregiver, diagnosis, palliative phase of illness and performance status), plus patient-reported survey at baseline and follow-up (3–5 days later for inpatient and 7–21 days later for community settings) (see Table 1). The survey included VOC and the Integrated Palliative Care Outcome Scale (IPOS). We report VOC at follow-up and change in IPOS between baseline and follow-up. Descriptive statistics characterise sample demographics and VOC responses, and chi-square statistic tests the association between VOC scores and IPOS change scores. SPSS version 22 was used throughout. Ethical approval was obtained from the Dulwich National Research Ethics Committee, London, UK (reference no. 124991).

Results

A total of 212 participants were recruited; mean age was 65.84 (standard deviation (SD) = 13.5) years, mainly with cancer (79.5%). We report on 137 participants who completed both baseline and follow-up surveys (Figure 1). Responses to VOC 1, 3 and 4 were reasonably normally distributed. Responses to VOC 2 were positively skewed with most participants indicating that palliative care was giving positive benefit.

Participants reporting that 'things had got better' (VOC 1) were more likely to have improved overall outcomes (reduction in IPOS total score: $\chi^2_{(2)} = 6.057$;

Table 1. Demographic and clinical details of participants.

Participant characteristics	Baseline (N = 212), N (%)	Follow-up (N = 137), N (%)
Age (years)		
<65	88 (41.6)	52 (38)
>65	115 (54.2)	79 (57.6)
Missing	9 (4.2)	6 (4.4)
Gender		
Male	100 (47.2)	67 (48.9)
Female	108 (50.9)	68 (49.6)
Other	1 (0.5)	1 (0.7)
Missing	3 (1.4)	1 (0.7)
Ethnicity		
White	189 (89.2)	124 (90.5)
Other	13 (6.1)	6 (4.4)
Missing	10 (4.7)	7 (5.1)
Marital status		
Married/partner	116 (54.7)	77 (56.2)
Other	91 (42.9)	59 (43)
Missing	5 (2.4)	1 (0.7)
Has a caregiver		
Yes	157 (74.1)	106 (77.4)
No	49 (23.1)	28 (20.4)
Missing	6 (2.8)	3 (2.2)
Lives alone		
Yes	82 (38.7)	50 (36.5)
No	127 (59.9)	87 (63.5)
Missing	3 (1.4)	0

(Continued)

Table 1. (Continued)

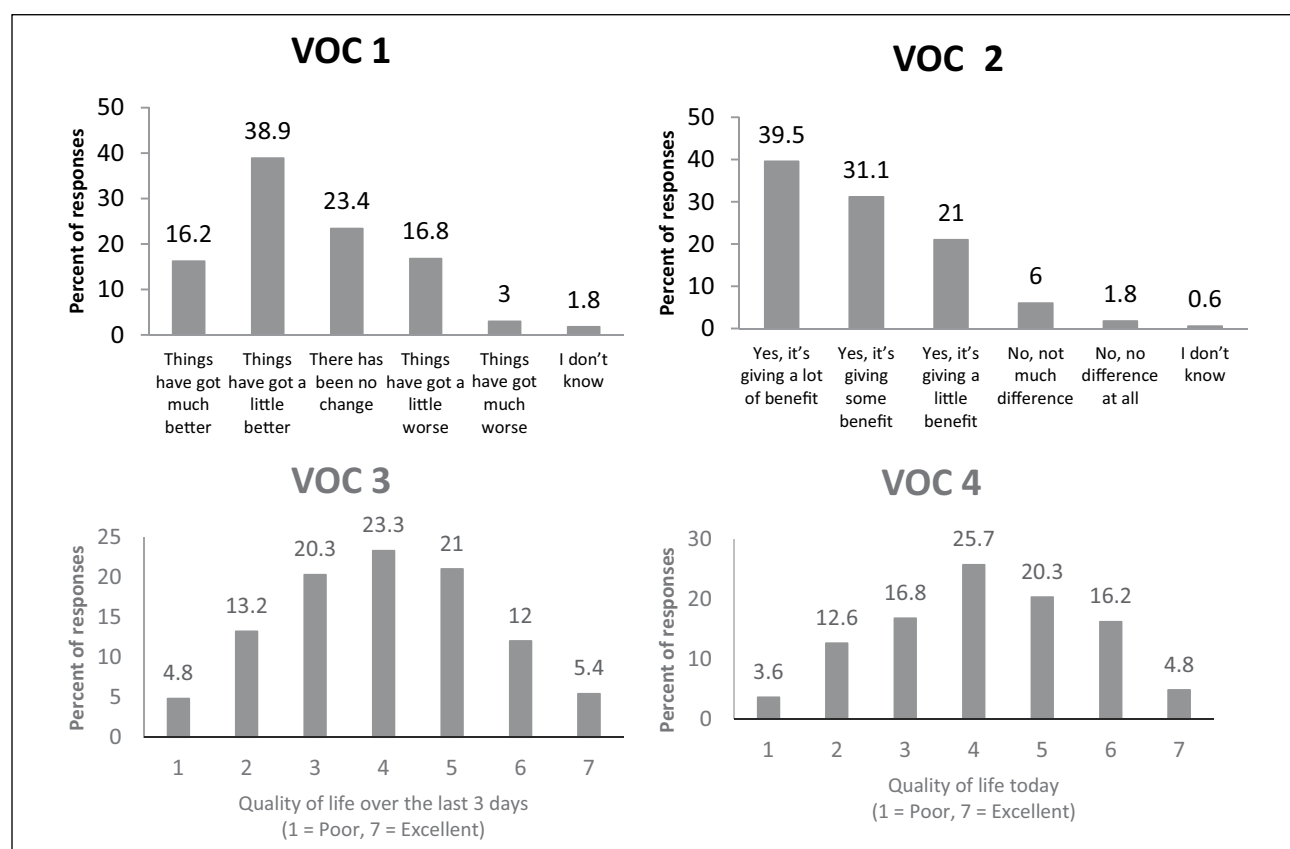
Participant characteristics	Baseline (<i>N</i> = 212), <i>N</i> (%)	Follow-up (<i>N</i> = 137), <i>N</i> (%)
Diagnosis		
Cancer	159 (75)	104 (75.9)
Non-cancer	41 (19.3)	25 (18.2)
Missing	12 (5.7)	8 (5.8)
Phase of illness		
Stable	93 (43.9)	65 (47.4)
Unstable	75 (35.4)	29 (21.2)
Deteriorating	12 (5.7)	24 (17.5)
Missing	9 (4.2)	19 (13.9)
Performance status (%)		
0–50 (poor status)	75 (35.4)	45 (32.8)
60–100 (good status)	128 (60.4)	73 (53.2)
Missing	9 (4.2)	19 (13.9)
Setting		
Hospital inpatient	48 (22.6)	27 (19.7)
Hospice inpatient	85 (40.1)	57 (41.6)
Community (home-based)	79 (37.3)	53 (38.7)
Geographical location		
London	70 (33)	42 (30.7)
Sussex	50 (23.6)	29 (21.2)
Kent	46 (21.7)	36 (26.3)
West Midlands/ Staffordshire	27 (12.7)	18 (13.1)
West Yorkshire	19 (9)	12 (8.8)

$p = 0.48$). There was no association between patients' report of benefit from palliative services (VOC 2) and changes in IPOS total scores ($\chi^2_{(1)} = 2.924$; $p = 0.87$), nor between changes in patients' quality of life (changes between VOC 3 and 4) and changes in IPOS total scores ($\chi^2_{(2)} = 2.410$; $p = 0.30$).

With regard to IPOS subscales, there was significant positive association between those reporting that 'things had got better' (VOC 1) and improved outcomes on the IPOS physical symptoms subscale ($\chi^2_{(2)} = 11.254$; $p = 0.004$). However, there was no association between reporting 'things had got better' and changes in the psychological or communication/practical IPOS subscales. Patients reporting benefit from palliative services (VOC 2) were more likely to have improved scores on the IPOS communication/practical issues subscale ($\chi^2_{(1)} = 4.743$; $p = 0.051$), but there were no significant associations between VOC 2 and other IPOS subscales. Patient-reported change in quality of life (between VOC 3 and 4) was not significantly associated with IPOS subscales.

Discussion

First, it is important to note that most participants reported that things were getting better and that palliative care was providing benefit. This was found across different settings and palliative Phases of Illness. Second, patients reported positive change more often when physical (rather than

**Figure 1.** Distribution of VOC responses at follow-up (*N* = 137).

overall, psychological or communication/practical) outcomes had improved. Third, we found that reports of positive impact of the palliative care teams was associated with improvement in communication/practical outcomes, but not with improvement in outcomes overall. This is an important finding as it demonstrates how much communication and practical matters influence the experience of care. It also illustrates that both outcomes and experience need to be measured if quality of care is to be properly understood. In line with our findings, Black et al.³ found that particular aspects of patient experience, namely, communication and trust in healthcare professionals, were strongly associated with better outcomes in surgery. A limitation of our findings is that – in this study – about one-third of patients did not complete the second timepoint, often due to a change in setting and loss to follow-up but sometimes because of deterioration in health.

This is the first study that has examined patients' responses to the VOC questionnaire. Further research is needed to understand how VOC relates to more generic experience measures, how it behaves over time and to test its psychometric properties. However, VOC is brief and easy to use on a large scale with patients receiving palliative care across different settings. Its uniqueness is that it is brief and easy enough to use for ill patients receiving palliative care, in order to provide patient-level feedback in real time, rather than the institutional-level indicators that are often used to assess the quality of healthcare services. It adds very little burden to professionals, enabling patient feedback while taking up little time or effort. We hope it will be of value for clinical practice.

Declaration of conflicting interests

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